Executive Summary

HISTORY

According to a recent Eagleton survey, cancer is the leading health concern among New Jersey's citizens. In 1999, a New Jersey Department of Health and Senior Services (NJDHSS) Internal Strategic Cancer Planning Team identified the need for a more systematic and integrated approach to cancer prevention and control and identified priority recommendations as reflected in the *Strategic Plan for Organizing Cancer Control in New Jersey* (1). One recommendation in the strategic plan was that the state develop and implement a comprehensive cancer control plan.

New Jersey has a rich history of cancer planning and public health efforts that provide a foundation for such a plan. The earliest planning efforts in cancer prevention and control involved the development of site- and risk-factor specific programs. Since the 1970s, cancer control stakeholders have made major contributions by establishing cancer awareness programs directed toward various New Jersey populations. These include a coalition to fight tobacco use, The Advisory Committee on Smoking OR Health, and several programs to provide free or low-cost cancer screening to the medically underserved. In 1992, the State Cancer Plan, initiated by a task force composed of approximately 50 representatives from key private and public organizations, outlined a comprehensive approach to reduce cancer mortality. All of the initiatives cited above, along with many other activities led by both public and private agencies, laid the groundwork for addressing the full spectrum of cancer control activities throughout the state in a coordinated and cost-effective manner.

In 2000, former Governor Whitman issued Executive Order 114 establishing the Task Force on Cancer Prevention, Early Detection and Treatment in New Jersey (henceforth known as the Task Force). The Task Force was charged with addressing the impact of cancer on New Jersey citizens. More specifically, the Task Force was authorized to evaluate historic, current, and emerging trends and produce a document that would become a blueprint for cancer control efforts in the state over the next five years. In conjunction with this process, the NJDHSS, along with the University of Medicine and Dentistry of New Jersey/School of Public Health and the New Jersey Commission on Cancer Research, hosted two educational roundtable programs. These roundtables fostered collaboration among cancer control stakeholders and represented a starting point for developing a new, more comprehensive approach to cancer prevention and control in New Jersey.

New Jersey began the formal process of developing a comprehensive cancer control plan with the appointment of the 16 Task Force members and the establishment of planning support from the NJDHSS Office of Cancer Control and Prevention (OCCP). The Task Force formally began its work with a meeting convened on January 29, 2001. The Task Force's first action was to adopt the Centers for Disease Control and Prevention's (CDC) operational definition of *comprehensive cancer control* as "an integrated and coordinated approach to reducing cancer incidence, morbidity, and mortality through prevention, early detection, treatment, rehabilitation, and palliation" (2). The Task Force further developed a mission statement, goals, and objectives based on the parameters of the Executive Order.

Utilizing the comprehensive cancer control framework developed by the CDC, the Task Force designated eight workgroups to undertake background research and strategy formulation for specific areas of the *New Jersey Comprehensive Cancer Control Plan*. Seven workgroups focused individually on specific cancer sites including breast, cervical, prostate, lung, melanoma, colorectal, and oral/oropharyngeal cancers, thus aligning Task Force efforts with the Healthy New Jersey 2010 goals relating to cancer. The Task Force recognized that the Healthy New Jersey 2010 goals were projected for ten years and allowed for further planning beyond the five-year implementation period envisioned for the *Comprehensive Cancer Control Plan*. The eighth workgroup addressed overarching issues that crossed multiple cancer sites and risk factors, such as advocacy, palliation, access to care, childhood cancer, and nutrition and physical activity. Additionally, the Overarching Issues Workgroup explored a number of emerging issues, including access to clinical trials, cancers associated with the Human Immunodeficiency Virus (HIV) pandemic and other infectious diseases, cancer survivorship, and complementary and alternative medicine. The Overarching Issues Workgroup recommended further consideration be given to these issues as additional evidence emerges.

The Task Force workgroups are comprised of decision-makers from medicine and nursing, academia, community health groups, public health representatives, health and human service agencies and organizations, and cancer survivors, all of whom are stakeholders in cancer prevention and control. Operationalizing the CDC's framework for comprehensive cancer control, the workgroups became an "organization of organizations" committed to planning and implementing together, using an evidence-based process. Workgroup members set about developing goals and objectives and prioritizing strategies based on a variety of data sources, including the New Jersey State Cancer Registry, a designated registry of the National Cancer Institute's Surveillance, Epidemiology and End Results (SEER) program. Epidemiologists dedicated to each workgroup provided planning data and current research, a model which was recommended by the CDC. This active and broad involvement by key stakeholders reflected a multidisciplinary, whole-person, population-based approach to service delivery that represents the core principle of the *New Jersey Comprehensive Cancer Control Plan*. Integral to the process has been the input of cancer survivors, and their wisdom and experiences have been noted throughout the *Plan*.

The planning stage of New Jersey's comprehensive cancer control initiative was complemented and supported by the guidance and counsel of the Battelle Centers for Public Health Research and Evaluation (Battelle) and was marked with a two-day site visit by two Battelle staff members to NJDHSS in May 2001. Their findings, summarized in a case study report, benchmarked the progress that had been made to date in comprehensive cancer control planning in New Jersey and recommended next steps. Battelle – instrumental in the development of the CDC conceptual model for comprehensive cancer control designed with input from six "model planning states" and six CDC implementation grantees[1] – assessed New Jersey's progress in the six core areas of the Conceptual Model. These core areas are (1) assessing/addressing the cancer burden, (2) enhancing infrastructure, (3) mobilizing support, (4) utilizing data/research/evaluation, (5) building partnerships, and (6) institutionalizing the initiative. Battelle found that New Jersey had a well-developed coordinating infrastructure, rich data resources, a high level of existing support

[1] The six model planning states for comprehensive cancer control were Arkansas, Illinois, Kansas, Kentucky, Maine, and Utah. The six CDC implementation grantees were Colorado, Massachusetts, Michigan, North Carolina, the Northwest Portland Indian Health Board, and Texas.

in terms of both funding and political will, and a firm basis for expert, broad-based planning in the composition of its Task Force. "New Jersey not only has the ingredients for a successful comprehensive cancer control planning effort – with well beyond the minimum needed in each of the core areas – but also has a considerable head start on institutionalization." "Institutionalization" is the end point of an ideal comprehensive cancer planning process, the point at which comprehensive cancer control becomes a new and widely accepted way of "doing business" and the planning body becomes an expert forum for debating cancer control issues (3).

TELLING NEW JERSEY'S STORY

The Task Force workgroups began by examining best practices from such states as Kentucky, Maine, Michigan, and North Carolina, who gave generously of their advice and expertise. With a total of nearly 350 volunteers, the various workgroups applied the CDC framework, which consists of four phases of development moving from "setting optimal objectives" to "implementing effective strategies". The phases are also incorporated into a cycle that allows for continual revisiting of efforts invested in cancer issues. The product of each workgroup, reviewed by external peer reviewers, was then submitted to the Task Force along with priority recommendations. The Task Force included in the *Plan* issues raised by its workgroups and subcommittees, along with their respective goals, objectives, and strategies. However, the Task Force also recognized that for successful implementation, the *Plan* must "start" somewhere. For this reason, the top priorities from each workgroup are presented below.

Access and Resources Workgroup – *Identification of Need*

Barriers in New Jersey can restrict residents' timely access to proper healthcare, thereby limiting their ability to achieve the best outcomes. Determining the unmet cancer care needs and barriers to our state's population – and the special subpopulations within it – may aid efforts to improve access to care. Community-level needs analyses are essential to guiding the cost-effective and efficient deployment of limited resources.

Advocacy Workgroup – *Internal Structure and Funding*

Advocacy has been incorporated as a major strategy for advancing the *Plan*, with the goal of ensuring all citizens access to education, screening, and quality cancer care. By building capacity through recruitment of key stakeholders, advocacy for funding of and support for the *Plan* can be fostered to assure its successful implementation for the benefit of all New Jersey citizens.

Childhood Cancer Workgroup – *Adolescent and Young Adult Treatment*

Cancer in adolescents and young adults is more common than in younger children. However, the survival rate for young adults has not kept pace for specific types of cancers seen in both groups. Educating healthcare providers about the availability of existing clinical research protocols and identifying how current psychosocial needs are being met are among the goals for improving care for the 15- to 19-year-old cancer patient.

Nutrition and Physical Activity Workgroup – ***Cancer Prevention***

Although the body of literature demonstrating the correlation between dietary intake and reduced risk of cancer is large and fairly consistent, many aspects of the relationship between diet and cancer are not completely understood. Evidence for the role of physical activity in reducing cancer risk is also accumulating. Educating all New Jersey residents about healthy eating patterns, healthy weight, and adequate physical activity for cancer prevention through a fully funded comprehensive nutrition program is necessary.

Palliation Workgroup – *Education*

Palliative care is likely to become the practice norm in mainstream U.S. healthcare in the coming decade, with the potential for New Jersey cancer patients in need of palliative care services very high. Despite advances, many New Jersey cancer patients still suffer from unmanageable symptoms. Alleviating barriers to effective palliative care by addressing the lack of awareness among healthcare professionals and the public is the first step to improving quality of life for New Jersey cancer patients.

Breast Cancer Workgroup – *Awareness and Education*

Approximately 1,400 New Jersey women will die from breast cancer in 2002, and New Jersey data reveal that, while white women have a higher incidence of breast cancer, black women have a higher mortality. In an effort to increase screening, increase early diagnosis, and ultimately decrease breast cancer death rates in New Jersey, education of many constituencies with a consistent message must be undertaken.

Cervical Cancer Workgroup – *Access to Care*

Cervical cancer is a preventable and curable disease when detected early. Those populations that are currently not being screened for cervical cancer in New Jersey must be identified. This can be accomplished through studies to develop a more comprehensive database of cervical cancer morbidity and mortality in the state and through analytic work that targets needed service improvements and barrier removal. The *Plan* proposes that populations at high risk for cervical cancer be identified and the reasons for that high risk investigated, thereby providing information needed to develop solutions for barriers to care.

Colorectal Cancer Workgroup – *Awareness and Education*

New Jersey has the highest incidence rate of colorectal cancer in the country for males, and the second highest rate for females. Education and enhancing awareness of the public, healthcare professionals, and third-party payers must be encouraged to facilitate dialogue, to increase the utilization of colorectal screening tests and to reduce personal, social, and economic barriers to screening. Only through recognition of colorectal cancer as a major health problem will New Jersey be able to effectively impact incidence and mortality rates from this disease.

Lung Cancer Workgroup – *Tobacco Control*

Lung cancer accounts for 25% of all cancer deaths in New Jersey and is the most common cause of death; however, both incidence and mortality are declining. In 2002, the American Cancer Society estimates that 4,900 new lung cancer cases will be diagnosed in New Jersey compared to 6,200 diagnosed in 1998. Tobacco control has been recognized as the most effective approach in the prevention of lung cancer. The Lung Cancer Workgroup, recognizing the ongoing efforts of the New Jersey Comprehensive Tobacco Control Program, recommends support of the long-range goals of this successful initiative.

Melanoma Workgroup – *Awareness*

The top priority of the Melanoma Workgroup is communicating the fact that malignant melanoma is a life-threatening disease through the development of a multi-level, multi-faceted awareness campaign. This awareness campaign, which will also be beneficial to those with non-melanoma skin cancers and other sites for malignant melanoma, is of particular importance to New Jersey with its active coastal community. The development of initiatives that target diagnosis through early detection and screening provide the opportunity to impact the state's rising melanoma incidence rate, which ranks eighth in the nation.

Oral and Oropharyngeal Cancer Workgroup – *Public Awareness*

Oral and oropharyngeal cancer requires special attention, as the public is only minimally aware of cancers occurring in this body region. Nor is the public aware of lifestyle behaviors that increase risk for these diseases, signs and symptoms of the diseases, and locations where oral cancer screenings may be obtained. Enhancing public awareness in New Jersey through a collaborative effort with local and national organizations will positively impact all populations.

Prostate Cancer Workgroup – *Public Awareness and Education*

Cancer of the prostate is the most prevalent of all cancers in men because of the slow tumor growth rate and improved survival rate. However, there is no scientific consensus on the effectiveness of prostate cancer screening in reducing deaths, and effective measures to prevent prostate cancer have not yet been determined. Until there is scientific consensus, empowering the public through education about early detection remains the most powerful tool. It is imperative to inform the public regarding the pros and cons of prostate cancer screening so that educated decisions about screening and treatment can be made.

WHAT THE FUTURE HOLDS

In a report prepared for the CDC, entitled *Essential Elements for Developing/Expanding Comprehensive Cancer Control Programs* (4), four elements are cited as essential for planning and implementation:

- State health department leadership and commitment
- Public-private partnerships

- Access to data and scientific expertise
- Resources

NJDHSS has demonstrated its willingness to dedicate staff, resources, and attention to initiating and maintaining comprehensive cancer control planning. The OCCP, on behalf of the Task Force, has coordinated efforts with private partners and state programs. This process has maximized the collaboration of multiple divisions within the NJDHSS, among them the New Jersey State Cancer Registry, Family Health Services, and the New Jersey Commission on Cancer Research. The OCCP has effectively communicated with a wide variety of stakeholders throughout the planning process and will continue as facilitator and coordinator throughout the implementation phase.

However, implementation of the *New Jersey Comprehensive Cancer Control Plan* will require intensive collaboration among its public and private partners. An impressive collaborative effort has already produced this document. Yet New Jersey's comprehensive cancer control initiative can only continue to grow by expanding the efforts of the nearly 350 volunteers who have already invested their time, energy, and expertise to make this *Plan* happen. As the workgroups transition into implementation teams, they will be networking with existing, successful programs. This will continue to build relationships, broaden membership, and expand cancer control activities to achieve the *Plan's* goals.

The cornerstone of implementation will be conducting a statewide Cancer Capacity and Needs Assessment that will bring together information on the cancer-related efforts of both public and private agencies into a centralized resource for New Jersey's many constituents. Access to data and scientific expertise is needed to assess needs and identify gaps in cancer programs and services. Community-level prevalence data are especially important to improving delivery of effective and appropriate interventions. Finally, the availability of adequate evaluative information is crucial, not only for effective implementation of the *Plan*, but also for development of future plans.

No discussion of plan implementation would be complete without addressing the need for funding. However, as the CDC points out in its *Guidance Document for Comprehensive Cancer Control Planning*, the ongoing activity of mobilizing support involves more than merely securing funding. It requires a broad campaign that will provide visibility, develop political good will, and enhance awareness of community leaders who can become advocates for both funding and implementing portions of the *Plan* (2). Current and new partners must be engaged in comprehensive cancer control, not only for their expertise, but also as key decision-makers who can advocate persuasively for and deliver on commitments to plan implementation.

The value of the *Comprehensive Cancer Control Plan* is better integration and coordination of cancer control activities among all New Jersey agencies and organizations. This collaborative effort will reduce duplication and improve the delivery of programs at the state and community levels. Ultimately, this will benefit every citizen in New Jersey. Together we can make a difference.

References

(1) New Jersey Department of Health and Senior Services. Strategic Plan for Organizing Cancer Control in New Jersey. Trenton, NJ: New Jersey Department of Health and Senior Services, 2000.

(2) Centers for Disease Control and Prevention and Batelle Centers for Public Health Research and Evaluation. Guidance for Comprehensive Cancer Control Planning. Atlanta, GA: Centers for Disease Control and Prevention, 2002. http:/www.cdc.gov/cancer/ncccp/guidelines/index.htm

(3) Abed J, Rose J. New Jersey Comprehensive Cancer Control Initiative: report from site visit on May 10 and 11, 2001. Arlington, VA: Battelle Centers for Public Health Research and Evaluation, 2001.

(4) Butter MD, Abed J, Hare M, Orians C, Rose J. Essential elements for developing/expanding comprehensive cancer control programs: design options for state health agencies. Final report prepared for the Centers for Disease Control and Prevention, Division of Cancer Prevention and Control. Arlington, VA: Batelle Centers for Public Health Research and Evaluation, August 2000.